

Caregiver Assessment Initiatives Results

Caregiver Surveys

3 VA Networks

- **VISN 10: VA Healthcare System of Ohio**
- **VISN 19: Rocky Mountain Network**
- **VISN 22: Desert Pacific Healthcare Network**



Survey tools

- **Caregiver Strain Index (CSI)**

- **Measures strain in relation to employment, financial, physical, social and time. 13-item scale. Robinson, BC. (1983). Validation of a caregiver strain index. Journal of Gerontology 38:344-348.**
- **A score of 7 or more on the CSI, may indicate the need for more in-depth assessment and intervention by a social worker**

- **Zarit Burden Inventory (ZBI)**

- **Evaluates subjective burden. Zarit S, Reever K, Bach-Peterson J: (1980) Relatives of the impaired elderly: correlates of "feelings of burden." Gerontologist 20:649-655, 1980**
- **A score of 17 or higher on the 12 item ZBI, may indicate the need for more in-depth assessment and intervention by a social worker.**

Process

- **Caregivers surveyed – VA Care Coordination Home Telehealth patients – Caregivers included both family (informal) and paid (formal) caregivers**
- **Surveys were either mailed, administered in person in the home or by telephone**
- **High risk referrals referred to Social Work Services or program leads**
- **Intention for 6 month follow/up survey on high risk caregivers**

Why support VA caregivers?

- **Caregivers contribute to a patient's ability to access care**
- **Caregiving significantly reduces the burden of care on a taxed healthcare system**
- **Caregivers who themselves stay healthy reduce the burden of care on a taxed healthcare system**
- **Caregivers who receive appropriate support may be better equipped to solve problems or prevent crisis**
- **Healthy and supported caregivers may be able to continue to provide ongoing, long-term and necessary care for veteran patients in their home**

Goals of the Pilot Surveys

- To contribute to the well-being and independent living of veteran patients by determining caregivers needs and through formulating the development of a standardized system of appropriate support
- To determine if caregivers experience a critical level of strain or burden in providing care for VA patients
- To support the need for regular caregiver assessment
- To promote referral to a social worker who could complete a more detailed assessment and initial care plan
- To support caregiver needs through timely referral to existing/available VA or community resources that may reduce level of caregiver strain/burden
- To determine the need for new programs or services that will enable caregivers to provide better care for veterans under the model of **“Right Care, Right Place, Right Time”**

Data Analysis Overview

- **328 surveys (291 useable)**
 - VISN 10 (55)
 - VISN 19 (120)
 - VISN 22 (116)
- Survey data merged with utilization data from the National Patient Care Database
- Descriptive and correlation analyses

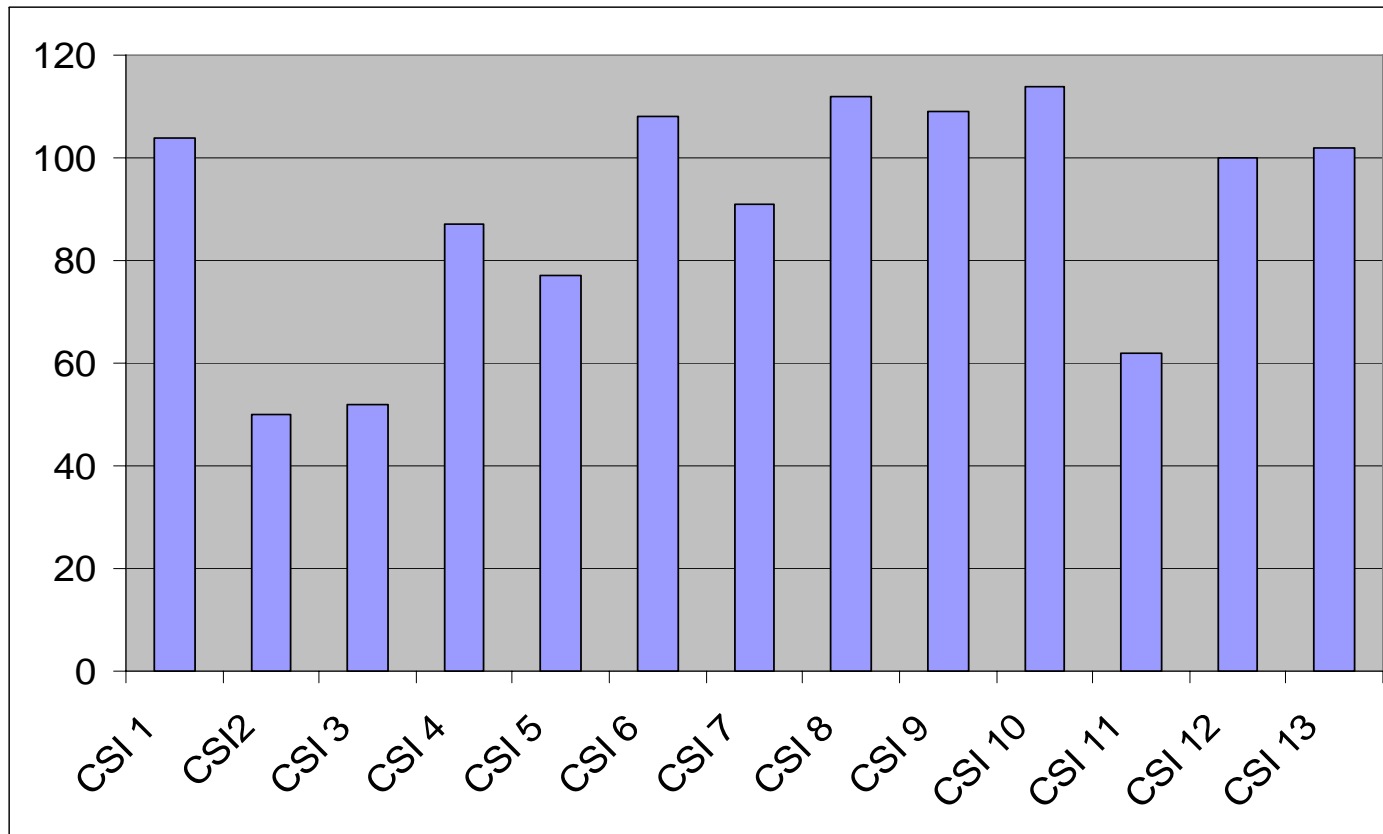
Veteran Demographics

Age	69 (± 10) years
Race	79% Caucasian
Gender	94% male
Marital	58% married 22% divorced
VA Eligibility	56% A-non svc 34% A-svc 6% C / G

CSI Overall

- **22% no stress (score 0)**
- **51% some stress (score 1-6)**
- **28% stressed (score 7+)**

Caregiver Strain Index Item Scores



CSI Items

<i>CSI Item</i>	<i>%</i>
Upsetting vet has changed so much	41
Emotional adjustments	40
Changes in personal plans	39
Some behavior upsetting	39
Sleep is disturbed	37
Completely overwhelmed	37
Financial strain	36

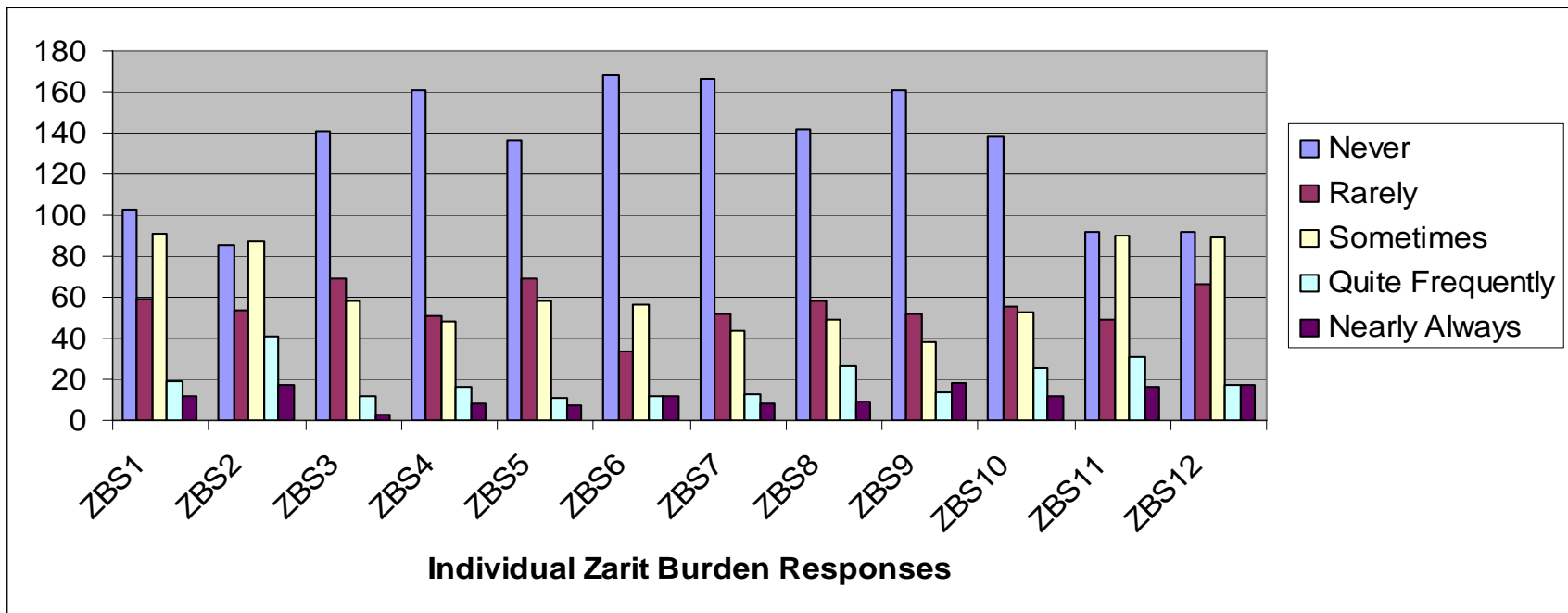
Zarit Burden Scale

- **ZBS full scale**
 - 27% high burden (17+)
 - 73% no or low burden (<17)
- **ZBS Screening (4 questions)**
 - 22% high risk for burden (8+)
 - 78% no or low risk (<8)

Zarit Screening Questions

- **Don't have enough time for yourself?**
- **Stressed between caring for relative & trying to meet other responsibilities?**
- **Feel strained when around your relative?**
- **Feel uncertain about what to do about your relative?**

Zarit Burden Survey Item Scores



Zarit Items 'Quite Frequently' & Nearly Always'

<i>Zarit Item</i>	<i>%</i>
Caring for relative and trying to meet other responsibilities	20
Do you feel you should be doing more for your relative	15

Zarit Items “Sometimes”

<i>Zarit Item</i>	<i>%</i>
Don't have enough time for self	32
Caring for relative and trying to meet other responsibilities	31
Feel should be doing more	32
Feel could do a better job	32

ZBS and CSI Correlation

	CSI		
	Caregiver not stressed (0-7)	Caregiver stressed (7+)	P value
ZBS Survey No Burden (0-16) Burden (17+)	179 (93) 14 (7)	15 (20) 59 (80)	<.0001
ZBS Screen No Burden (0-7) Burden (8+)	185 (96) 8 (4)	24 (32) 51 (68)	<.0001

Survey Scores Across VISNs

	<u>VISN 10</u>	<u>VISN 19</u>	<u>VISN 22</u>	<u>p</u>
<u>ZBS Survey</u>				
No Burden (0-16)	45 (85)	88 (75)	70 (64)	
Burden (17+)	8 (15)	29 (25)	39 (51)	.02
<u>ZBS Screen</u>				
No Burden (0-7)	45 (85)	96 (82)	77 (71)	
Burden (8+)	8 (15)	21 (18)	32 (29)	.04
<u>Caregiver</u>				
Not stressed (0-7)	46 (84)	84 (78)	72 (62)	
Stressed (7+)	9 (16)	24 (22)	44 (38)	.004

VISN Variation

- **Geographic differences (urban – rural)**
- **Survey administration (face-to-face vs. mailed)**
- **Casemix / enrollment differences**

Caregiver Stress/Burden and Veteran Utilization Data

- **No significant differences comparing high stress and low/no stress caregivers**
- **No significant differences pre and post survey administration**
 - **Small sample size**
 - **Not all surveys were administered at CCHT enrollment time**

Recommendations

- **Define the population. Should the veteran live with the caregiver? How independent/dependent should they be?**
- **Conditions that caregiver is providing care for**
- **Establish a standardized way of surveying caregivers**
- **Collect information on facility / VISN**

Recommendations (cont.)

- **Measure level of caregiver comorbidity as that likely impacts how much they can care for veteran, i.e., medical conditions, depression**
- **Primary caregivers vs. others who help, paid help**
- **Demographic information for caregivers, e.g., gender, age, relationship to veteran**
- **Size of the caregiver/veteran family, those who lives with veteran**
- **Caregiver learning needs**

Selected Caregiver Responses

- We are fine now, but will need help in the future, I am stressing because I don't want to lose my husband to his illness. I am really scared.
- We are both in our early 80's and help each other. I have macular degeneration. My husband helps me, I help him.
- When my husband was discharged, respite was provided every six months. This respite was so welcome. Now the rules have changed and VA provides respite only once a year.. Whoever made that decision does not understand the exhaustion. I am exhausted and it has only been 4 months since my last 2 week respite.
- I wish I were stronger. I weigh about 120 lbs and I have trouble moving my husband around.
- I am sick myself due to heart condition, blood pressure and I just had a knee replacement. Trying to be a good wife and care for my husband, but it is hard.
- I have been helping x since 1994. I have been told I would receive financial assistance but haven't received anything.
- I help this individual, but because I do, I have no time for family or friends. I will continue to help him, but it is extremely distressing.
- It is difficult to watch someone you love and know that there is nothing you can do to change the situation.
- It is difficult knowing my husband is in great pain, and there is nothing I can do to help him.
- Because this person needs constant care, I am unable to work so financially we and our 3 year old child suffer.
- My stress comes from also dealing with my own illness, so it often is difficult to help my brother.
- Patient has a tendency to get violent and verbally abusive. She keeps problems to herself, but often hurts others feelings.
- I feel overwhelmed by things that need to get done, that I can't get around to doing. He is hostile, frustrated angry and lacks cooperation.
- Thank you for asking. No one has ever asked how I am doing.

Selected Caregiver Responses

- I am the patient's wife and have serious health problems of my own. I am seventy and tire very easily. Transportation is a problem and I need help with housework. - My big worry is getting him to his doctor's appointment. Also the price of gas and the fear of losing my job because I need to take time off.
- I would like to be better informed about X's illness. It would help me to take better care of him.
- He gets mood changes and angry for nothing. He always has to be right and he is often confused. I would like the doctor to give him something to pipe him down. I don't want him to know I am telling you because he will blow his stack.
- I am myself recovering from ovarian cancer so I don't have the strength I use to, to be able to care for him
- Patient: I have no relatives or friends to act as a caregiver. My phone buddy is my only contact to the outside. I will need a caregiver should I have a downturn.
- I am the only person who can care for my dad and he leaves 25 minutes away. I am called at all hours for appointments, and trips to the ER. Dad is legally blind.
- I am concerned what I will do when his health deteriorates and I cannot care for him alone, or afford to hire extra help.
- I can't move him in and out of the car. I also am the caregiver and do not drive.
- I feel overwhelmed because of my husband's emotional state. Sometimes I feel that it would be beneficial for him to have some type of counseling. I also see he is in pain and it appears that no one is responding medically or else they are taking their time to do so. It is very frustrating.
- I have lost jobs in the past due to providing his care. It is taking a toll emotionally and financially. I love him very much and will care for him till the end, but I am very afraid of what is ahead for us.

More detailed assessments could include:

- Financial costs of caregiving, housing, transportation, legal concerns, employment concerns/status
- Caregiver health, personal illness and disability, spiritual well being/access, personal relationships with veteran, other family members and support systems
- Marital status, ethnicity, languages spoken, interpreter needed
- Distance from facility, length of time providing care, distance of caregiver to patient, services received, ability to deal with crisis
- Need for education, level of understanding of patient diagnosis/prognosis, skill in providing appropriate diet, dealing with incontinence, administering medications, assisting with patient mobility or transfers, PT/OT needs, managing money, managing household work
- Ability to plan for the future and ability to access and secure services and support needed
- Greatest concerns in caring for the veteran
- Overall level of strain
- Caregiver level of confidence in providing care

Initial care plans might include

- Counseling: Individual/Family
- Support group
- Education/training
- Medical evaluation
- Legal/financial consultation
- Transportation
- Home health services
- Home maker/chore assistance
- Respite (In home or out of home)
- Hospice
- Help with placement